

Abstract

A summarized report of a facility's medical information about a cancer/tumor/case as it appears in the patient's medical records. The data items contained on this report encompass the information requested by SEER and NAACCR, including text summary fields and excluding recodes and other derivable data. Generally, this report is compiled by hospital staff or by a registry staff member sent to the facility specifically for this purpose (an **abstractor**)

Ideally, every cancer/tumor/case would have an abstract for each facility at which it was diagnosed or treated. In practice, information gathering is not considered complete until there is at least 1 abstract, although path-only and death certificate only CTCs are released to maintain reporting levels

Active Follow-up

Refers to a focused effort of the follow-up, rather than passive follow-up which occurs as a side effect of other processes. Active follow-up is more expensive and time consuming than passive follow-up, but is necessary because it provides a review of every patient. Patient sets that have not been updated via passive follow-up are handled individually. Active follow-up is needed if the last date of contact is too 'old' and the vital status is living. These patients (or their physician or informant) are contacted. The process requires time to determine who needs to be contacted, time to determine the best method of contact, as well as time to track whether a response is received or a different contact method is necessary. The three primary methods are sending a patient list to a physician, sending a patient list to a hospital, and contacting a patient (or informant) directly

Aging

This term is used to describe the period of time between diagnosis and attempts to obtain an abstract. Usually, the registry waits to obtain an abstract for a given cancer/tumor/case for 4-6 months after diagnosis (the exact time is based on registry policy). This delay allows all medical records for the patient to become incorporated into the medical records folder. It also allows time for treatment to be initiated (or even completed) so that a reasonably complete picture of the CTC can be gathered at one time (i.e. during a single visit) with only a relatively small time lapse from diagnosis. While a more complete picture would be possible after a year, we want the data as soon as possible and experience has shown that most of the first course of treatment information is obtainable after the 4-6 month window

Byte-based Duplicate Record

A record which meets a stricter definition of duplicate than Match-based Duplicate Record. The exact same record has been received from a facility for the patient/tumor - there are no modifications to the values on the record, it matches byte for byte and is strictly a retransmission

Cancer/Tumor/Case

An instance of the disease of interest. Generally speaking, a Cancer/Tumor/ Case is a neoplasm with topology, histology, and behavior codes within the SEER (local or special study) guidelines. While this is usually a cancer and a tumor, some code combinations are not truly tumors and others are arguably not cancer. Case is sometimes used interchangeably with "tumor" or "cancer" but case can also be used to refer to a person in our database

In the documentation, we sometimes use 'Tumor' instead of Cancer/Tumor/Case, usually within a standard data item name. We also use Cancer/Tumor to refer to an instance of a disease that has not yet become a case in our database. We frequently abbreviate Cancer/Tumor/Case as CTC

Case-Finding

Now called Screening, the process of discovering Cancer/Tumor/Cases that were previously not

reported by a facility. This process helps to prevent under-reporting and involves searching listings of health records (disease index, death lists, etc) or transmitted files of individual records (path reports, abstracts, etc) for signs of possible CTCs.

All facilities are supposed to report cancer/tumor that they discover. The registry is interested in obtaining an abstract from every facility that has experience with the cancer/tumor and may have to do case-finding to get information from all relevant facilities

Case-Finding List

Now called **Abstraction Facility Lead**. A list comprised of possible cancers detected through the screening process. These would generally contain some identifying information for the patient, the CTC and a facility (DC cases wouldn't normally have facility information). Mostly, this list is the result of screening and could also be thought of as a 'to be abstracted' list. Leads sometimes come from processes other than screening

Computer Edits

Process that compares data values to rules. SEER edits are primarily implemented in the SEER*Edits package that IMS has designed and coded. These edits return Success or Failure flags. If a person reviews the data for a Failure and decides that the data supports the values of the items, there are some cases where an override flag may be set (a.k.a. review flag, however, there are only about a dozen of these). From previous discussions: error, warning, inconsistency does not seem to really fit the output truly being generated by SEER*Edits. (One could view a failure as an error, a warning as a 'failure' with an override set, but I'm not sure how an inconsistency would fit in.

Consolidate

The process of taking many values for a particular data item and selecting the best value for that item. The value selected may be different from the original set of values. That is, other data items may be used to make the final decision. Text is usually very helpful in making the decisions (especially at the tumor level). The process of consolidation can cause follow-back if a best value can not be selected based on available information. There is a certain amount of editing inherent to consolidation. Decisions may be made based on editing rules affecting the data item, and the new values must pass the edits (or be intentionally overridden) before being accepted permanently as the best value

DCO

Designates a CTC as 'Death Certificate Only', that is, all the information came from a death certificate and no further information is available.

In terms of process, this is a death certificate that mentions cancer and does not match to a tumor set. After attempts to follow-back for this cancer/tumor/case fail, registry marks it as DCO with a complete status. Here, follow-back is the attempt to find a source, that is a physician or facility which can create an abstract about the tumor. Such a source may be listed directly on the death certificate. There are times when no source is ever found. Or, it may be possible for the registry to trace the appropriate source through the source listed on the death certificate. Sometimes the final source does not have information to create an abstract. This can occur when the diagnosis and treatment occurred out of state, when the CTC was diagnosed clinically; when the patient only went to a physician's office; when the patient was never treated at all; when the CTC was not histologically confirmed; and when the CTC was missed in routine reporting for a hospital.

Registries need to have the DCO rate of 1.5% or less after follow-back. Some standard conventions used when abstracting DCOs: Date of Dx = Date of Death; Stage at Dx = Unknown; Histologically confirmed = No; Coded as Untreat

It is very important that the registries can report that a patient/CTC started as a DCO but is now something else (and what it is now –facility, physician’s office, etc). This would likely be checking to see if there is a ACD for DCO flag turning it off

De-Identified File

A data file that does not contain patient identifiers, such as name, social security number, address, etc. A unique key that is not based on or related to any of the patient’s other information may be provided. While IRB approval and collaboration agreements may be necessary to obtain these files, the rules are generally less restrictive because patient privacy is not at risk

Death Clearance

The process of trying to find more complete information on cases which are only known through death index/death list/death file and death certificate. If no other information can be found, the case becomes a DCO

Extract

A file which leaves the registry. This may be an identified or de-identified file.

Facility Update Report

A list or report sent to each facility, either periodically or by the facility’s request that contains data values which have been modified by the registry for that facility’s patients. The first time a patient is included in this report it may contain the entire facility view of the patient set. The goal is to keep the registry’s and facility’s information in sync. However, this is not always successful since the facility is not forced to accept the registry information. Facility update reports would include death information obtained from a death certificate

Facility View

The summary of the facility’s understanding of the patient and CTC information. This information may not represent all the cancer/tumors a patient has developed, as the facility would not necessarily know about cancer/tumors diagnosed and treated at another facility. It is possible that a facility’s view does not include the most accurate information about the patient or a CTC. A facility’s view includes what the facility knows, not just what they did. If they have been informed of events that occurred elsewhere, they would ‘know’ that information. While registries wish to notify facilities of better information, they cannot force a facility to accept the information and the facility view should not be updated until there is confirmation from the facility that the information has been accepted

NOTES:

- New Mexico would like to store, in a Facility View, the names of all facilities within the same organization that have seen the patient.
- Some registries may use a Facility View to store what is actually an Organization’s view.
- While maintaining this would increase the amount of time an editor spends in consolidation, it would enable the registry to provide consolidated patient information to the facilities with cancer registrars

Fillable Request

A request that the registry has the ability to fill, that is, the data have been collected, the requested media is available, etc. This differs from validity considerations, that is, whether the registry should fulfill the request

First Course of Treatment

The medical practitioner’s initial plan of therapy to control or remove the cancer/tumor. This can

include surgery, radiation therapy, chemotherapy, hormone therapy, immunotherapy and other therapies such as new protocols being tested, etc. The sequence of the treatments is important. We also track whether or not the patient received the recommended therapy and a reason for not receiving the therapy, if available. Since some of these therapies happen over an extended period of time, the first date (i.e. of a course of chemotherapy) is tracked. Also, registries typically wait several months after diagnosis to gather the abstract information so that these therapies can occur (or not). (SEER requires a registry to collect first course of treatment only, however some registries (CT, DT) may be collecting more than this.

Follow-back

The SEER registries' process of clarifying data they have gathered by going "back" to the original source. This differs from follow-up in that follow-up specifically refers to the gathering of survival data (is the patient dead or alive) while follow-back is the gathering of all other types of information and not survival status

Follow-back can be triggered when information is missing or conflicting (the conflict may be in one variable values or values among multiple variables may conflict)

Follow-back can be as brief as a phone call or can involve the sending of a letter to a source

Follow-up

The SEER registries' process of gathering survival data on all patients in their database. Information gathered for follow-up purposes includes Date of Last Contact, Vital Status (alive/dead at last contact) and Cause of Death when appropriate. Other data items are maintained for tracking purposes (type of last follow-up, physician of record, informant contact information, etc.). This information is used to produce survival statistics; therefore, every effort is made to keep the last contact dates current

Health Record

Record that contains health related information. This includes death certificates that have cause of death information, pathology reports, abstracts, etc. These are primarily used to initiate case finding, but are also used for passive follow-up (especially the death certificates). These are either sent to the registry or are created by the registry (for example, abstracts)

Identified File

A data file which contains patient identifiers. These are strongly protected by local and state confidentiality rules. IRB and collaboration agreements are required to obtain these files and the registries have very strict rules regarding the use of these types of files

Information Request

Written or oral correspondence asking for data collected by the registry. This would include requests from individuals for rates for a specific cancer and requests from researchers for a file for analysis. This would also include management requests, such as reports on the number of abstracts collected, error reports, etc

Match

A decision that new information for a patient, a patient/CTC or a patient/CTC/facility represents knowledge about a patient, patient/tumor or patient/tumor/facility that already exists in the database. This decision is based on the similarities of identifying data (name, SSN, DOB, etc, for patient; histology, laterality, date of diagnosis, etc for tumor; facility ID number, name, address for facility) and the overall level of confidence that the two sets of data are related. Several possible matches may need to be examined to determine if it is a true match

Match-based Duplicate Record

A record from a facility for the patient/tumor when one was already received from that facility. This record matched according to some algorithm, e.g. LA's key-type match, but does not imply that the information has been completely verified against the original. While changes should come in on correction records, it is possible that the Match-based Duplicate Record is actually a correction record that was not marked as such. Match-based Duplicate Records can be sent immediately to consolidation

Medical Records

A patient's medical record is a facility's profile of a patient and all of their visits. These are kept at the facility and are never supposed to be removed. Data items and text for an abstract are obtained from these medical records

Passive Follow-up

Refers to the follow-up process that occurs as a side-effect of other information gathering processes of a registry. Every record that comes into a registry through other processes is compared to the patients in the database. Follow-up information is updated if a match is found. This also refers to a single effort expected to update follow-up information for a large number of patients. This may be requesting or matching to death certificate files, DMV, voter(s) registration, CMS (Medicare/Medicaid) enrollment files, other state and national health files, the national death index (NDI), hospital discharge summaries and so on. This is cheaper and faster than active follow-up but is not complete

Path only

A designation used for a CTC to indicate that it is a path report only case, that is, all information in the tumor set came from a path report and no further information is available. Path reports may include the standard pathological report or a hematology report. In terms of process, these are path reports that mention cancer and do not match to a tumor set. After attempts to follow-back for this cancer/tumor/case fail, the registry marks it as path only with a complete status. Follow-back here is attempting to find a physician or facility which can create an abstract about the tumor. It may be mentioned on the report or the registry may know associated facilities for the lab which generated the report. The registry may be able to trace an appropriate source; may be unable to find any source; or the source may have no information for an abstract. The source may have no information when diagnosis and treatment occur out of state, when the CTC was clinically diagnosed; when the patient only went to a physician(s) office; when the patient was never treated; and when the CTC was missed in routine reporting for a hospital

Registries need to have the path only rate at **xxx%** or less after follow-back. The path only designation may also be used for oncology, radiology, cytology, hematology or autopsy reports.

Patient Information

Data items, independent of the diagnosis, specifically related to the person that are independent of the diagnosis. They may be updated as new information is received. These include name, maiden name, vital status, current address, date of birth, etc

Patient Set

All information related to the patient. Patient Set includes the patient and CTC information with multiple layers representing registry and facility views.

Rapid Case Ascertainment (RCA)

Expedited process for gathering cancer information. For certain special studies, time is of the essence (for example, a study which desires an interview with pancreatic cancer patients). The information

being collected may be time sensitive or in danger of being lost because of short life expectancy in the cohort. If a record is eligible for such a study then the information is made available to the special study immediately. Follow-back responses to clarify or complete information for the case will be forwarded to the special study as registry policy dictates. The abstracting of a record tagged for rapid case ascertainment would get elevated priority and would not be delayed for the standard 'aging' of a case

Please note, this may require additional work by the registry staff. Usually, these cases are obtained from path reports. Registries may need to get additional variables for the study, but this is **not** considered abstracting. It is usually too soon to do abstracting and they may have to go back and do that too. Registries usually charge for this service

Also, who they choose to apply RCA to is affected by many things. First and foremost, is this involved in an RCA special study? Second, how much of my current work is RCA? If breast, prostate, colorectal and lung are all being collected RCA, they may chose to do everything RCA. Third, how convenient is it? If it is the hospital down the street that I pass every day or they are on the same system as the registry, they may choose to do all cases from that facility as RCA. If the hospital is only visited once every 6 months, nothing may be RCA (they gather the information as they can)

Record

A group of related data items that a registry wishes to incorporate into their database. While records frequently arrive in an electronic file, they can also arrive on paper. Information may also be obtained from a fax or from a phone call and tracked as a record. If the media on which the registry receives the information is non-standard to the registry, the data must be copied to the appropriate media. A paper-based registry would want all their 'records' in hard-copy, a totally electronic registry would not. Most registries fall somewhere between these two extremes

Registry View

The summary of the registry(s) understanding of the patient and CTC information. This may not include all the cancer/tumors a patient has developed (because of residency), but should contain the most accurate information about the patient/CTCs that are reportable. Multiple facility views are incorporated into a single registry view. Therefore, the registry view is generally a more precise understanding of the patient and the related CTCs than a single Facility View. The registry view should not contain variables other than those in the Facility View (except possibly a complete list of which facilities are included)

Registry-Controlled File

A file which is internal to the registry. This file remains under the control of the registry, who grants access via accounts and passwords. The registry may provide training in the use of the file and can restrict access if desired. These files may be identified or de-identified

Report

A summarized 'parcel' of data collected by a SEER registry (such as incidence rates for cancer x for the last N years) or data about the operations of a SEER registry (such as the number of abstracts done by facility). This includes SEER*Stat output, the Cancer Statistics Review, web sites with statistics, annual reports, ad hoc information requests, etc.. Reports about registry operations may include reports about the gathering of cancer information and staff work output, but would **not** include payroll reports. Reports can be produced according to a schedule or by request

Standard Format

A report, extract or registry controlled file that the registry expects to produce on a regular basis; or a template of a general format that can be used when creating specific reports, extracts or registry

controlled files. Examples of standard formats are the reports generated by SEER*Stat

Submissible

Describes a group of data items (generally speaking, the same items that are found on an abstract) that have been reviewed/edited and are considered available to be submitted (to SEER, NAACCR, etc). This is not meant to imply that no more changes can be made to the values. New information can certainly lead to a change. It is possible that the group would be tagged as 'not Submissible' until the new information was assimilated, but that may not necessarily be the case. For example, the registry would probably not change the submissible status because of a change to marital status, but would definitely do change the status if a change was made to histology which could result in a change to the number of tumors in the patient set

Supplemental Record

A record that contains **no** health-related information. Supplemental Records include records from the DMV, voter registration, etc. There are some mortality records that only contain the date of death and not the cause of death. These are considered to be supplemental records. Supplemental records are used to validate name, address, Social Security Number, follow-up dates, etc

Tumor information

Data items either specifically related to the Cancer/Tumor/Case or data about the person at the time of diagnosis. These would include date of diagnosis, histology, behavior, EOD, site specific surgery, address at diagnosis, age at diagnosis, etc

Valid Request

A request that can be legitimately filled according to

- federal, state, and local law
- privacy agreements between the registry and facilities, registry and medical practitioners, etc.
- registry rules (for example, a rule may be that incidence rates are not released to insurance companies at the zip code level)